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## **How might we best undertake research on donor-conceived persons' views about their conception?**

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Debates concerning disclosure in donor conception comprise both ethical and scientific dimensions. Others (see, for example, Gollancz, D. (2001) 'Donor insemination - a question of rights'. *Human Fertility*, 4, 164-167) have argued the ethical merits. This commentary focuses on scientific issues and, in particular, what sorts of research methodologies might most appropriately be applied to - and inform - these debates.

The positivistic approach to scientific inquiry, the assumption that 'real' knowledge is based on 'objective facts, ie. data that can be independently tested through observation, dominates clinical research, to the extent that the controlled study, and in particular, the Randomised Control Trial (RCT), is claimed by many as the 'gold standard'. Here, I am not challenging the role of the controlled study in respect of clinical research (although others have done so). However, I do challenge the assumption that it is the only credible approach to research - against which all other methodological approaches are deemed inherently deficient. There are a variety of well-tested and widely accepted social science qualitative methodologies that operate according to different rules that apply to the controlled study. But simply because they are different does not mean they are inherently 'worse' (or indeed 'better'). Neither does it mean that these approaches are conducted any less systematically, sceptically or ethically (Robson, C. (2002) *Real World Research*: Blackwell, Oxford).

The methodological approach chosen must be 'fit for purpose'. If we want to better understand a particular phenomenon, we need to choose a method of enquiry which has the best chance of achieving this - so different methods are required for different subject matters. Bhaskar makes this point graphically: 'it is obvious that one can no more set out to experimentally identify...the causes of the French revolution than one can contemplate interviewing a gene' (Bhaskar, R. (1979) *The Possibility of Naturalism: A Philosophical Critique of the Contemporary Human Sciences*. Brighton: Harvester, p. 30 - cited in Robson p. 35).

The controlled study approach to the question whether knowledge or ignorance of donor conception makes any difference to the donor-conceived person can follow one of two routes. First, two matched groups of donor-conceived people - one that knows about their conception and

one that does not - can be identified and subjected to various standard tests of psychological and socio-emotional adjustment. Four important caveats must be mentioned here. First, the tests have inherent limits, since they effectively pre-determine the focus of study (while this a clear advantage under certain conditions, it is less so in novel areas where much remains to be discovered). Second, given the uniqueness of all human beings, the 'matching' of groups is impossible in a realistic sense - researchers can only do their best to control for the more obvious variables that might account for differences between different groups. Third, such research can only apply proxy measures for the impact of ignorance or knowledge of donor conception, since the one issue that cannot be directly addressed with research participants is the nature of their conception. Fourth, by definition, the true nature of the research must be withheld from the research participants. While this would be a significant consideration where the donor-conceived person is old enough to give his or her own informed consent, it might not be considered especially problematic in the case of young donor-conceived children whose parents are both aware of the nature of the study and have consented to their children's involvement. Even so, there is broad agreement within social science circles that even young children are capable of giving their assent to participating in research and, in order to do so, should have the nature of the study explained to them in language that they can understand. A further potential problem arises from the claims of a number of donor-conceived people who have learned about their conception in adolescence or adulthood who have commented on previous awareness of 'something being different' in their family. It is not out of the question that such an individual, recalling having been involved in a research study as a child, might decide to find out what the research was about by locating and reading the published papers.

An alternative approach in the controlled study tradition is the pre-test, post-test study, where measurements are taken at the pre-and post-intervention stages. Such a study would also be totally reliant on proxy measures, at least for the pre-disclosure stage, while the disclosure itself would need to be significantly stage-managed (controlled). Such an approach would appear to be ruled out on both methodological and ethical grounds.

Thus, there are clear limits to the contribution of RCTs in this particular area. However, this does not mean that meaningful research cannot be undertaken. Indeed, it is precisely in such areas that competently-conducted, rigorous, ethical and methodologically-sound qualitative studies can increase our understanding of what is 'rich and real' about donor-conceived people's experiences. Indeed, while qualitative research does not provide 'proof' in the RCT sense (a proof which is in reality unachievable), it can provide what is so often lacking in the RCT, an insight into the world as experienced by its participants.

Removal of the legal protection of donor anonymity in the UK has been subject to considerable debate, bringing together a variety of viewpoints. While these often place different emphasis on the value of quantitative and qualitative research, they all seek answers to questions which can best inform on outcomes for donor conceived people. In order to achieve a more productive dialogue between different research traditions, there needs to be both increased awareness of the different methodologies and a recognition that there are other and - in the right places, better - ways to do research than that provided by the RCT.

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